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Participation in a support group from the perspective of family caregivers of Alzheimer‘s disease patients

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Abstract

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Aim: The aim of the study was to identify, describe and analyze approaches positively affecting care provided by family caregivers to the patients with Alzheimer's disease with focus on caregivers' perceptions and experience regarding personal participation in the support group.

Methods: The qualitative cross-sectional descriptive study design was adopted. To gather empirical data semi-structured interviews with family caregivers was used. Twenty caregivers were recruited between January and April 2016. The data were analyzed by thematic analysis.

Results: Three themes emerged reflecting positive impact of personal participation in a support group on caregivers: Solution-focused optimism, Practical help and Feeling of companionship. Psychosocial support from professionals and others in similar situation was also stressed with an emphasis on approaches already being used and verified by others members of the group.

Conclusions: Study results indicate the importance of belonging to support group perceived by family caregivers of patients with Alzheimer's disease.

Keywords: family caregiver, patient with Alzheimer's disease, support group, interview, thematic analyses

Introduction

In the empirical study we want to highlight the importance of experiencing survival participation in the support group for family caregivers. Such experience provides lessons for professional work and aids to development of its professionalization in the socio-health sector.

Patient with Alzheimer's disease can occur in any family, any social class, and any ethnic group and gender. Nursing and social care for a family member suffering from Alzheimer's dementia is demanding from the beginning, and exhausting emotionally as well as physically. The disease is progressive, with a slow start and duration for several years. Alzheimer's disease is a challenge for the whole family (Rachel, Turkot, 2015, s. 60). The family with an affected member finds itself in a stressful situation, in the need of practical, mental and material support from healthcare professionals and the government. Nursing competencies include complex approaches for assessment of the role of caregiver and mutual relationship between a caregiver and care-receiver for the estimation of problems and needs of a family. Assessment of a caregiver involves evaluation of a caregiver's role, lifestyle, impact of a current daily program and duties on his or her physical, mental and social aspect of health. It will also depend on the behavior, rate of caregiver duties, what kind and range of involvement in social and recreational activities, economic means, environment and equipment for care provision will be selected. Besides that, it includes observation and stress symptom evaluation of a caregiver (Kurucová, 2016, s. 23). The goal of caregiver's strain assessment is recognition of changes in the stressful situation, options of sources for social support, revealing of risk factors of the strain and assessment of coping strategies for the stressful situation. Social workers come in contact with the family of an ill person in several phases of the disease. Competencies of social workers are much wider, especially regarding social and health care, and they are not only in relation to a family, but mainly to an ill member of the family. This means especially social work in a direct contact with patients in specialized social service facilities by non-pharmacological approaches, but also with patients in home environment by cognitive activation.

World Health Organization (WHO, 2017) recommends increasing the amount of information on support groups and establishment of support groups cooperated by professionals (coordinated interdisciplinary cooperation) such as: nurses, social workers, psychologists, physicians and others.

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Aim of the study

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Sample

To participate in research participants were addressed by personal contact in a specific support group of twenty persons. Criteria for participant selection were as following: regular participation in the support group during minimum 6 consecutive months and voluntary participation in the research. Other criteria were not specified. The interviews were conducted in central Slovakia. Every interview took 20 to 60 minutes. Participants consented to participate in research before interviewed.

Participants were in relationship to patients with Alzheimer's disease in various family relations, as stated in table 1. Average age of female participants was 56 years; average age of male participants was 45 years.

Tab. 1. Overview of research participants' family relationships

Females in relation	n	Males in relation	n
Daughters	9	Sons	5
Daughters-in-law	3	Husband	1
Sisters	2	-	-
Total	14	Total	6

Methodology of the research

The qualitative cross-sectional descriptive study design was adopted. The study is based on collection of data by semi-structured interviews with family caregivers – participants of the support groups involving relatives of patients with Alzheimer's disease in Slovakia. Semi-structured interviews were focused on questions about positive experiences from participation in a support group, perception and importance of verified approaches as well as reasons for participation. Interviews were recorded with the help of recorder and subsequently were transcribed into written record.

For data analysis we used the method of thematic analysis (Braun, Clarke, 2006, p. 83). Silverman (2005, p. 26) mentions that based on qualitative research paradigm we deal with understanding of human behavior regarding reference range of the participants themselves. For illustration, the answers of participants in the text are made in italics.

Results

Caregiver's perception has elements from personal participation in the support group and there are three themes emerging from thematic analysis reflecting approaches that positively affect the management of care of patient with Alzheimer's disease from caregiver perspective: 1. *Solution-focused optimism*, 2. *Practical help*, 3. *Feeling of companionship*.

Solution-focused optimism

"By participation in the support group I got tailored information. I knew what to do and what not to; I can try what the others tried and it worked. It is not general information, but information about our loved ones, about us and about what we can do." (65-year-old daughter). The patient's family does not need general information but orientation of operative approaches, multiple views on a certain situation that guarantees the success of solutions. A 51-year-old daughter-in-law says: *"Each problem of my mother-in-law has several solutions and I have not tried all yet – this is what I have learned from the support group."* Diverse views on the same problem from several group participants create mutual optimism for care management. A 58-year-old daughter also explains the importance of being focused on verified approaches: *"I always confirm whether I am doing right regarding the approach to my mom."* Many family caregivers live in a hope that transforms to their approach in the care for their close person. They consider hope to be a positive emotion which helps them to find some value in hopelessness and gradually set to management of the caregiver role.

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Practical help

Participants view practical help as a factor positively affecting care for a close person at several levels. Some of them get practical help from the other family members (children, grandchildren, siblings) who are useful in the situations like a ride to a doctor, purchase of a medical device or financial support. Others also get practical help from facilitators of a support group. *"Facilitators answer my email queries promptly or always take my phone call and advise immediately."* (59-year-old sister). Some family members also use help provided by caregivers or nurses from home care agency or neighbors who help them in a daily care. Participants perceive devotion of professional or nonprofessional time of others as practical help. Practical help is viewed from several perspectives and always has certain importance in the management of care needed. Often it is not help with some practical or common issues, e.g. household works, but mainly devotion of time to enjoy the other person.

Feeling of companionship

Willingness to share common worries and joys in an open communication and by the of exchange experience creates a feeling of companionship. *"What we are here is more than a family. We have developed deep friendships that only we can understand."* (51-year-old daughter-in-law). Feeling of companionship is one of the themes positively affecting general care of the patients and personal participation in a support group. *"The feeling that I am not alone means a strong support for me."* (50-year-old son). Feeling of companionship has a motivation meaning in social behavior and is equally positive for all the involved. The importance of companionship is in the willingness to help each other which is significant in care of the patients with Alzheimer's disease regarding progression of the disease and care needed.

Caregivers also stressed the importance of personal participation into the work of support group. The benefits for caregivers were described in three areas as: 1. Knowledge development and exchange of authentic experience, 2. Health protection of family caregivers, 3. Support for caregiver role management.

Knowledge development and authentic experience exchange were the most frequently repeated reason of participation in a support group stated by participants, specifically gaining the information related to progression, course and prognosis of the disease and related care. The stages of the disease are also the base for care flexibility and demands for a family caregiver. Although currently it is possible to find sufficient information in mass-media sources including the net, caregivers prefer personal contact in a support group. "*Information in a support group means an open door for better understanding of Alzheimer's patients. What suits me very well is that I do not have to study, just schedule two hours and do not have to waste energy and time on the Internet and reading required literature."* (57-year-old daughter). Contact with facilitators as well as with other group members is also very important. *"It is admirable to see experts in the support group working. It is obvious that they care about feedback, honestly try and do it all with devotion."* (47-year-old daughter). The environment of support group is useful not just for obtaining new information, but also for sharing members' own and mediated experience. *"Obtaining necessary information and experience exchange between us is the greatest help. The strongest support for me is credibility and authenticity of experience."* (57-year-old daughter-in-law). Healthcare information to all the participants is interpreted in a proper form, understandable for a common person. In the support group everybody can ask questions, no question is stupid or funny and each is answered not only by an expert, but also by other participants. Information obtained in this way helps family members prepare for next stage of the disease and related strain and care.

We also consider the perception of the health protection of family caregivers as important.

"Only in the support group I can feel that somebody worries about me and provides care... just for me. Usually it is me who has to provide care more than 24 hours daily." (56-year-old daughter). Another participant (57-year-old daughter) comments: *"Participation in the support group can be compared with a big, heavy bag that I am not able to carry, but suddenly somebody appears – a person that understands how heavy the bag is – and helps me to carry it."* Protection of mental and physical health is a priority to retain care provision by family caregivers. The support group creates space for getting strength for next days by relaxed, intimate and safe atmosphere in the group and also creates networks for social relations and social life.

Experts help by their approach of creating good atmosphere in the group, by providing understandable information to the group members and by providing support of caregiver role management. A 43-year-old son stated in the interview: *"Now I can handle the accusations of my mom that I have stolen her something in a much better way. I am already prepared for them and have proactive approach to coming stress. I am well informed. This does not break me anymore as in the beginning, when I blamed myself."* A 51-year-old daughter-in-law finds supportive *"encouragement from qualified professionals dealing with this problem. I am grateful for the amazing humane approach."*

It is more than demanding to manage daily care for a close person, to work, take care of household or even school-able children. By participating in the support group, caregivers gain acknowledgement, praise and stimulation. A 56-year-old son who has been regularly attending the support group for fourth year, states: *"I do not know how I would manage the care for my mommy without the knowledge obtained in the support group. I have already lost my personal freedom and friends. I have only three things left: my mommy, trust in God and the support group."* Helping professionals consciously work on enforcing the family caregiver role. Long-term care for a patient requires governmental intervention (healthcare, terrain and ambulant social services) in combination with care of existing sources (family care). Only in this way, the strain is proportionally distributed.

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Discussion

Family care is a kind of primary care provided in a home environment of the ill family member. Kurucová (2016, s. 35) states that for solution of strain situations it is important how caregiver and other family members assess and interpret the situation, and how they view the seriousness of stressors and troubles related to them. If the situation is assessed as uncontrollable and unsolvable by the family, family problems caused by a stressor are so significant that the family might not be able to align situation requirements with possibilities thus several essential changes in family system will be needed, or the family may become dysfunctional which can create a crisis. Home environment is an important element, mainly in care for a senior due to a lower adaptability caused by higher age. Care for a patient with Alzheimer's disease requires a long-term help provision emphasizing sticking to life stereotypes, calm communication and respect to disease progression. By Tabaková and Václaviková (2008, s. 84), family caregivers feel fatigue and need relief from strain and social interventions, mainly by a form of consultation. Relatives in the role of family caregivers have to change their settled life habits and replace them by others, more proper ones for management of various situations brought by everyday life with the ill family member. At the same time, they have to cope with the fact that their close person requires a different quality of attention, love, patience, time and help than in previous years. Family members can feel negative emotions such as not believing persons they care for, shame, anger, sadness, loneliness, helplessness, guilt... and very few positive emotions in the situation. Family caregivers lose their freedom because the situation does not allow them to live their own life. All the attention and duties are focused on the needs of the ill person. Mental strain involves constant attention and observation of patient's condition, flexible reactions to requirements and changes of the patient, demands on memory, and responsibility for results of work, independent decisions and respecting certain rules. Besides that, we can also observe the impact of care for a chronically ill patient on family relations and in social area. The most frequent are a lack of family support and changes in role distribution in the family (Kurucová, 2016, s. 45). The main dilemma is distribution of the time between care for an ill family member and common household as well as care for own children. Time for oneself is extremely limited. Buijssen (2006, s. 77) states that almost all caregivers tend to show contradictory and mixed emotions. They love their partner or relative, but on the other hand they feel anger and annoyance. Some caregivers constantly swing between a desire to take care of the ill one and a wish to live their own lives, have hobbies, visit friends. Norheim and Dombestein (2015, s. 24) state that exigency of suitable communication with helping professionals about how caregivers imagine or want to care for their relatives is a basic precondition to enforce caregiver role management. They claim that caregivers in their research confirmed how they often manage the everyday care for their ill relative when they see that daily activities make sense for the ill family member as well as for a family caregiver. Callaby et al. (2012, s. 94) says that even the end of intensive care for a close person can be a prelude of emotional disorder or even a breakdown of the family caregiver. The way how to overcome this change is an essential task for social and health care services.

Hanisková (2006, s. 333) describes one of the most important elements for dementia care, the education of caregivers, advice and help provided to a family (20 % to 60 % of them suffered from depression). This element is especially based on the information that many family caregivers suffer from depression, usually requiring a long-term treatment and help of other family members and helping professionals. This way a so-called vicious circle is created. Prevention of depression is required and is possible to be maintained in the form of participation in the support group of caregivers with the same problem. In case family caregivers go up to the borders of their own abilities, their organism can collapse as result of a long-term strain, resulting in hospitalization of such overburdened family member. Therefore, it is necessary to provide help and support to family caregiver, so that the care does not mean an unsurpassable strain. Support can be also provided by social backup involving the family, close friends, neighbors, colleagues, community and professionals. Hrozenská et al. (2008, s. 112) underlines the importance of social backup in social work, meaning certain friendly relationship of two people with mutual trust and closeness and with the aim of helping the other better manage an unfavorable situation they have found themselves in.

By coordinated care for families with flexible personalized services there is a time-delay in long-term institutional care for persons with dementia (Sulkava et al., 2009, s. 2205).

Support group has priceless importance in meetings, experience exchange and acceptance and delivery of feedback. These interactions at the same time offer the group members an opportunity to learn more about themselves. Apart from the members of a group, this process is significantly helped by a professional – group facilitator (nurse, social worker), as this person can understand needs of a family caregiver better. The common view of participants is that it is encouraging to hear and know that others have similar problems, that they are not lonely in such situation. Unexpressed feelings are one of main reasons why people experience troubles. We found out that by mutual exchange of thoughts and experiences with the others they learn how to best cope with their own emotions. Knowing the feelings of others in a similar situation leads them to say openly how they feel deep inside. The role of a family caregiver is demanding and complicated and it is difficult to cope with it alone. For participants a support group is a place where they feel free and where there are people that understand and help each other. The support group provides them with an emotional support and social backup. Participants stated that together with practical advice and mutual help, these meetings are also a great mental help. By the mentioned facts we can say that participants in meetings of support groups obtain more knowledge about the disease, do not feel lonely, enforce the management of family caregiver role, increase their confidence in strain management and protection of their own health and have chance to identify with the others within the group.

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Conclusion

Alzheimer's disease affects all members in a family, not just patients. Family caregivers therefore become "hidden victims of dementia". Research of approaches positively affecting family care in relation to personal participation in a support group proved the need of meeting the people who undergo similar experience to be another type of social service in the frame of social work with families. An important role in a support group has a facilitator – nurse/social worker providing the participants with consultations, understanding and encouragement regarding specific care for patients with Alzheimer's disease. Interdisciplinary and coordinated cooperation in social and health care sector in which a nurse and a social worker participate, is essential to ensure quality of care provided and support not only for a family member suffering from Alzheimer's disease, but also for the family caregiver. Is is a challenge for educational institutions to create flexible curriculums for preparation of future helping professionals for a work with family caregivers.

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